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The Tuskegee Syphilis Study and Other Barriers to African American Participation in AIDS Clinical Trials

Madeleine Mashon



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ABSTRACT and METHODS

Despite African Americans composing 13% of the US population, they account for 51% of all reported AIDS cases between 1985 and 2002. Yet, due to a variety of sociocultural, structural and economic factors, many African Americans are uneducated about or distrustful of HIV/AIDS research methods and research-related procedures and terms in general. Researchers are struggling to find African Americans for screening and enrollment in AIDS clinical trials, which is critical to the development of new antiretroviral medications. "Without adequate representation of racial and ethnic minorities it is difficult to assess the ramifications, if any, of race and gender on HIV treatment regimens" (Cargill and Stone 906). Understanding these barriers to enrollment and developing strategies to combat them are essential to forming more successful minority recruitment methods in HIV/AIDS research.

To establish this link, I examined numerous focus group studies, surveys, questionnaires and scholarly articles that evaluated the willingness of African American populations to participate in health research, the obstacles impeding their enrollment, and strategies to increase their participation. I was especially interested in the role the Tuskegee Syphilis Study played in these enrollment decisions, and whether it or other factors were more influential in their decision-making. I conducted research database searches including "African Americans with HIV/AIDS," "the Tuskegee Syphilis Study and distrust toward medical research," and "methods to increase minority participation in health research." The majority of my sources were retrieved from scholarly, secondary and peer-reviewed sources such as medical journals.



Onlookers watch as Dr. Walter Edmondson takes a blood test from an unidentified Tuskegee Syphilis Study patient.

CONCLUSION

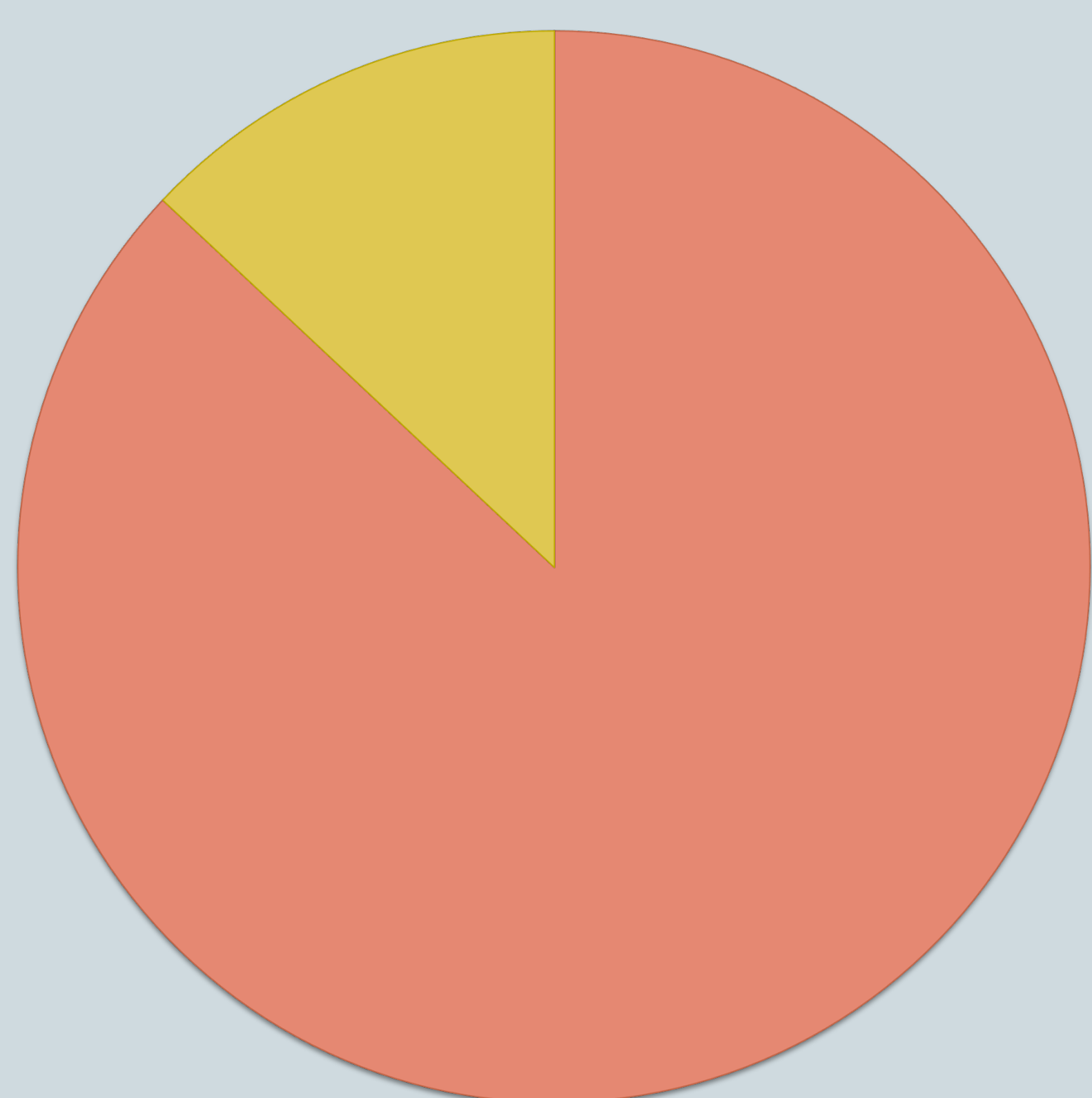
Due to a number of factors, African Americans are vastly underrepresented in health research, specifically, in HIV/AIDS clinical trials. It is vital that their representation expands so that researchers may further assess the implications of race and ethnicity on antiretroviral medications, ensure that population's access to safe, reliable healthcare, and decrease the number of HIV/AIDS-related deaths among minority populations.

Many of the root causes of the unwillingness of some African Americans to enroll in health research are entrenched in historical abuses such as the Tuskegee Syphilis Study, creating feelings of fear and distrust. Other causes stem from poor or misplaced knowledge of health terms and procedures, provider biases and various structural issues.

It is the responsibility of the healthcare professional to provide a safe, educational and culturally-sensitive environment. I do not doubt that researchers have the tools to mend the disparities that exist between some African Americans and our health system.

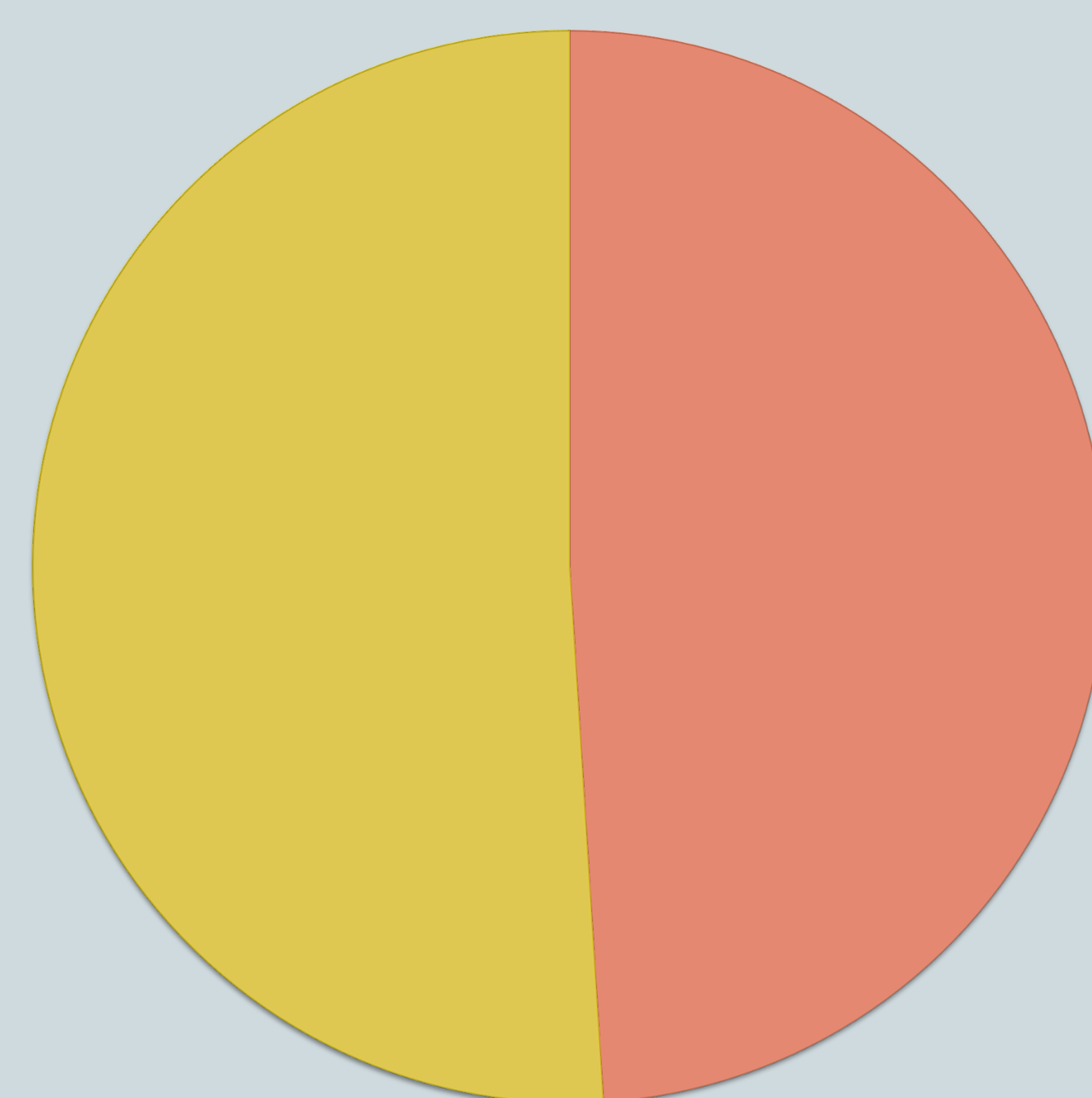
African Americans Account For...

13%



Total US Population

51%



AIDS Cases in the US (reported 1985-2002)

RESULTS

The studies revealed that the following serve as major barriers to African American participation in health, specifically HIV/AIDS-related, research:

- Distrust rooted in the Tuskegee Syphilis Study and other historical abuses
- Poor or inadequate knowledge of healthcare procedures and terms
- Provider biases
- Structural issues, such as childcare and transportation

Although the Tuskegee Syphilis Study has discouraged some African Americans from participating in such research, a combination of other factors has played a greater role in their decisions to participate.

In order to increase African American enrollment, it is crucial for healthcare professionals to...

- Educate minority populations about the benefits and drawbacks of health research
- Address any fears, misconceptions and conspiracies by providing factual information about historical abuses and healthcare procedures and terms
- Eliminate any biases from their own practices
- Form trusting patient-provider relationships
- Provide culturally sensitive recruitment strategies such as peer-driven intervention

Increasing African American participation in AIDS clinical trials is the only way to treat these issues, and it is imperative that health professionals take the necessary steps to do so.

ACKNOWLEDGMENTS

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